Keratoconus Group

Newsletter Spring 2021

Inside this Issue

Notice of AGM and speaker meeting

Working During Lockdown

KC Coffee Mornings

Help at Work

Cross Linking Special

Research News

Thank you Alicia

Sight and Sound Technology

Fight for Sight Small Grant Awards

Well done Ashley

Mugs & T-shirts

Notice of Annual General Meeting

Saturday 20th March 11am on Zoom

With lockdown continuing, this year's AGM will be held on Zoom. Whilst we miss the face to face contact and the chance to meet others on the KC journey, this is an opportunity engage with our members across the country. Our guest speaker will be **Dr Bita Manzouri**, consultant eye surgeon at Queen's Hospital, Romford. Working on the front line, Bita will be able to bring us up to date with modern treatments for KC. She will explain what is available and what we can expect. As we all know, living with KC is a balancing act and our members need and want information to guide their decisions. Bita is well placed to answer your questions. The Q&A is always an informative part of our meetings. To join the meeting on the day, please e-mail chair@kcgroup.org.uk and we will send you a link a few days in advance.

You do not need to stare at a computer video screen all meeting with, KC light-sensitive, eyes. You can choose to join in by an ordinary telephone call. You will be able to hear all the other people, like a telephone conference, or an old-fashioned party line.

Working during lockdown by Caroline Dyer

Committee member Caroline Dyer has contributed her thoughts and experience of working from home during lockdown.

Reflections from lockdown are many, but contemplating them from a Keratoconus perspective has been interesting.

Positives

We are good at washing our hands and being resilient. For many of us we have to adapt to situations at both home and work and know the importance of trying to protect our eyes/selves from infection. We don't have to contend with variable vision and lighting affecting our ability to travel to and from the workplace.

Challenges

Eye drops and lenses require us to touch our faces more often. Social distancing makes it harder to see things, I usually like to get closer to see people's expressions, read signs and find information (saying that, I haven't been out much but, as lockdown starts to ease, this is likely to change). Familiar environments have changed to allow for social distancing and so familiar places are different to navigate.

Adaptations to a different way of working

I am fortunate in that mostly my job can be done remotely from home. I have found that while everything is done in a virtual way, screen time has increased and I did not expect to spend my working day sitting at the dining table.

Things to consider if not already in place

Are you able to bring screens and office equipment home? I've got my larger screen at home which has made a huge difference. Have you picked the best spot at home for lighting? Is there a better place, the kitchen or bedroom that you haven't considered or is it worth changing location part way through the day.

Diary Dates

All on Zoom

KC Coffee Morning
20th February 2021
At 10:30

Sight and Sound Technology
9th March 2021
At 18:30

AGM and Speaker Meeting
20th March 2021
At 11:00

Remember to keep an eye on our website or Facebook page for future events

Different ways of meeting

In my working world we are using Teams as our virtual meeting space. Socially and as part of the Keratoconus Committee group we have used Zoom.

Time in lockdown has been a rollercoaster of emotions for most people, but it has given us time to think, read and consider our lifestyles. This includes a working environment that has changed, certainly in the short to medium term and maybe forever.

Changes to home working set up

When the news came in late summer that I would be working from home until at least Christmas and now may be Easter and beyond, we were encouraged to take more time to look at working conditions. As both I and my husband were now co-working from home, we needed to create spaces that would work for longer.

So I am fortunate in that the local authority that I work for allocated a budget of up to £100 to purchase equipment to enable home working. Speaking to friends, it did seem that many larger companies and organisations had set up a covid fund for this purpose. It is worth investing in a proper office chair and desk. We have now been asked to complete a DSE (Display screen equipment) assessment and we are then able to apply for funding in addition to the £100 should further equipment be required.

Things to consider

- Undoubtedly you are spending more time staring at a screen so remember to take regular breaks (this was an outcome from an occupational health assessment that I had prior to covid)
- Be strict on start and end times, just because your desk is now 12 paces from your bed, you shouldn’t be working longer hours!
- Let your line manager know if you are struggling and
- ask if there is support for further equipment and/or more flexible working hours
- Take a proper lunch break away from your screen, spend some time outside or maybe go for a walk
- Remember that your employer has a duty of care to offer the support that you need

KC Coffee Mornings

The attendance at our KC Coffee mornings is growing and it is proving to be the perfect place where members can discuss problems they are experiencing and enabling others to pass on advice and coping strategies. It became apparent that working conditions were a big issue hence Caroline's article and we decided to devote our December meeting to that subject. Coincidentally Visionary, an umbrella organisation for sight loss charities, hosted a conference and there we were introduced to **Zsuzsanna Hybel**, who works as employment manager for the Essex charity Support 4 Sight. Zsuzsi offered to attend our Coffee Morning which turned out to be our most successful to date.

Our January meeting was hosted by **Amy Marsh** and focused on Cross Linking. Both meetings threw up many issues which are summarised in the next pages.

We shall return to our general coffee morning on 20th February 2021.

Please feel free to drop in or out at any time. Just email a request for the link to chair@kcgroup.org.uk we'd love to hear from you.

Zoom Meetings

You don't need any technical knowledge or have sophisticated equipment to take part. Any computer, tablet or smart phone will do.

If you are not confident and would like to practice first, just email ukkeratoconus@gmail.com and we will send you a link to have a one to one session to make sure you are confident to join one of our Coffee Mornings or the AGM and speaker meeting.

Help at Work Coffee Morning

You don't need to be registered sight impaired to be able to get help at work. The Equality Act covers anyone who has a health condition which is likely to last 12 months or more and that has an impact on their day to day activities at work.

If this applies to you and you haven't previously told your employer about your keratoconus, the first step is to disclose your condition and this should be 'formal' (ie not just a conversation in the corridor, but with a written note made) so that there is a record of your KC. A useful aid to this conversation is the 'Keratoconus at Work' leaflet that you can download from our home page https://www.keratoconus-group.org.uk/index.php/access-to-work/. The employer then has a 'duty of care' and should make reasonable adjustments to enable you to do your job. There is no legal definition of 'reasonable' but it might be something as simple as moving your desk so you are by a window with natural light at your back, providing a larger computer screen or changing your shift pattern. When arranging a meeting to discuss reasonable adjustments with your employer, it is useful to have someone else in the meeting with you ie a work colleague, a union representative or even a family member or friend. It can be quite daunting to be facing your manager and a HR person on your own.

Access to Work is a government scheme designed to help the employer make the adjustments you need by providing a workplace assessment (this could include your home if Covid, for example, means you are working from home) and covering most of the cost of any adjustments needed. Access to Work contracts companies or charities to carry out the assessment (It is important that the assessor has experience of dealing with sight problems). It can cover providing technology or equipment that would make your tasks easier, it can cover the cost of travel to and from work if you are no longer able to drive and there is no public transport you can use, or it can cover a personal assistant to help you do tasks you can no longer do (up to 20% of the content of your job).

Even where the employer has made some reasonable adjustments for you, it is worth getting a workplace assessment (which could also involve your occupational health department if there is one). Technology is changing so fast that you will often not be aware of the possibilities that are out there that could make your life easier at work. A workplace assessment will be tailored to your needs - vital when no two people with KC are the same, and an adjustment that works for one person won't always suit another. Most jobs these days involve working at a PC screen, sometimes for the whole working day, and the light sensitivity, ghosting, halos, changing vision over the working day can all make this challenging. Solutions may be as simple as adjusting the brightness, contrast, font size, background colour, font colour, taking regular breaks from the screen, or more sophisticated eg a software package such as Zoomtext. Whatever the solutions, they need to be tailor made for you and include training on any new technology packages. (NB The RNIB Technology Team is a great source of advice on what is available. They can be contacted on 0303 123 9999 or tfl@rnib.org.uk).

There is lots of help available to support people to obtain and remain in employment

You should tell your employer that you are applying for Access to Work and then complete the application form https://www.gov.uk/access-to-work . After the assessment, the ATW assessor will produce a report (sent to you) and a list of recommendations sent to you and to your employer. ATW will cover between 80% and 100% of the cost of any technology or equipment they recommend, with the employer asked to contribute up to 20%, depending on the size of the company. If taxi fares are agreed to cover travel to/from work, you would contribute what you would have paid to drive or use public transport. An award from ATW is made for three years though changes can be made if your circumstances change in this time and can be re-applied for after the initial three years.

For more details on the help available, do look at all the other resources on the Keratoconus at Work page on our website, including the excellent videos made by **Zsuzsi Hybel** for the Macular Society, but which are just as relevant to people with KC.

Cross-linking Special Coffee Morning

Amy began by telling the meeting she had had cross-linking (CXL) seven years ago in both eyes a week apart. She had the treatment privately soon after her diagnosis. She found recovery was different in each eye. Although the lead up was more stressful before the first procedure, when she didn't know what to expect, recovery was much better than she'd expected. With the second eye, although she was more relaxed, recovery was more painful and she struggled to open her eyes in the first 24 hours.

The discussion that followed covered a wide range of experiences, with some people having had CXL several years ago and others whose treatment had been only a few weeks ago. One young member had CXL five years ago when she was just 13 and found it had really helped that eye - important when KC in the other eye was too advanced for CXL. She also described how hard it had been for her at school with poor vision, and the difficulties of explaining to people that she had a condition she could not control and that changed over time. Some had had only one eye treated, others had had CXL in both eyes, usually a few months or a year apart, although David described having CXL done in both eyes at the same time. He had general anaesthetic for the procedure, although most had it done under a local anaesthetic. There was also a mixture of people who had CXL done on the NHS and others who had had it privately.

Mel described her experience four weeks ago. She was anxious before the procedure but felt very relaxed on the day. Because her cornea was thin, she was first given drops to swell the thickness. Her other eye was covered. Her consultant chatted to her through the application of the riboflavin drops and then the eight minutes of shining UV light into her eye.

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The whole procedure lasted about 30 minutes using the now commonly used accelerated application of UV light. She went home with a variety of drops, including antibiotics and drops for pain. While some people described having quite intense pain for a couple of days, Mel said hers wasn't too bad although she did stay in bed in a darkened room listening to podcasts for several days. Light sensitivity, tingling sensations and a feeling of having gravel in the eye were described by several members in the days following CXL. Mel took 2 weeks off work but then booked another 2 weeks as she didn't feel ready to stare at a computer screen all day. (Members gave each other advice on getting help from their employer in the return to work). Also common was the experience of vision changing in the weeks and months following CXL. People were told it would take 6 months to a year for vision to settle down. Amy described having yearly scans post CXL to monitor her corneas, and being discharged after several years of stable vision.

KC is most often diagnosed in the teens or 20s, and CXL is not usually offered on the NHS beyond the age of around 35 when most KC naturally stops progressing. For several in the group, KC had developed in their 30s or 40s and they were interested in the option of CXL. Ash described his experience of having CXL done privately when he was 35. His vision is now stable, so he did not regret having the procedure, although it has caused dry eye (a possible side effect of CXL) which he did not have before. Martin had CXL on the NHS in his 40s, but this was to stabilise KC that had begun to return in his grafted eye, an uncommon use of the treatment.

Andy's experience of dry eye led to him describing his dry eye spa treatment. This involved LidPro, a small rotating scrub to exfoliate the eyelids, followed by riboflo thermoflo treatment, which heats and unclogs the meibonian glands (the glands that get blocked and cause blepharitis and dry eye). It is available privately at Moorfields http://dryeyespa.uk/ and other clinics with plenty of videos on youtube of the treatment. Another member mentioned using an eye mask heated in microwave.

The Zoom group appreciated hearing the variety of experiences - useful for those contemplating CXL and helpful for those who had had the treatment and could compare how others had fared. There are constant advances in CXL - one member mentioned the trials of cross-linking targeting specific areas of the cornea.

Research News - Keralink

Many of you will have read about this research study in previous newsletters. Keralink is a multi-hospital study looking at the safety and efficacy of collagen cross-linking in children aged 10 to 16. It is a random controlled trial, with half the sample of 60 youngsters getting cross-linking, and half getting 'standard' treatment of glasses or contact lenses. The young people in the trial were then followed up for 18 months. Analysis of the main trial has now been completed and the results will be published in the spring. We will, of course, then publish the results on our website and in the next newsletter. As reported in a previous newsletter, Keralink has since received funding to continue the follow up for a further two and half years in order to assess the longer term effects of cross-linking in this age group.

A huge thank you to Alicia and her family

Alicia raised an amazing £1989.27p for the KC Group by doing the Million Step Challenge. This involves doing 10,000 steps for 100 days (equivalent to 500 miles). That was clearly too easy for Alicia, and she completed the Challenge in 44 days, ending on the Hill of Fare (near Aberdeen) accompanied by her daughter, granddaughter, Logan and puppy Piper (see photo). Alicia contacted the KC Group when her young grandson, Logan, was diagnosed with keratoconus.

On her JustGiving page, Alicia wrote - "This is a charity very dear to me. They have helped me to understand what keratoconus is and its impact on individuals and their families. The progress being made in the treatment of this condition is fantastic, but more needs to be done."

Logan had successful CXL treatment at Moorfields last year and is now doing well in contact lenses. Our grateful thanks go to him for raising an impressive £510 by walking with his grandad around Lake Muick on the Balmoral Estate. Our best wishes for 2021 to all the family!

Sight and Sound Technology - if only I'd known

Sight and Sound are hosting a webinar for us specifically tailored towards KC. The webinar takes 6 or 7 cases covering people at different stages of their lives – children, teens, students at university, young people in work and those at a later stage in their lives. They will look at how the condition manifests itself and map the impacts into various scenarios and look at how the technology can support those with the condition. The webinar has a mix of real time demonstrations and presentations showing the technology in use.

The topic "If only I'd known….", has been chosen because it is what people always say. Technology is developing so fast we simply do not know what is out there. You can now get what looks like a small pen and clip it to your glasses. It contains a camera linked to your smart phone by Bluetooth. It will read a menu just by running your finger over its surface and when you go outside it will read the shop signs. If you walk into a room it will tell you if someone is there either sitting or standing and even their name if you have seen them before.

Someone the other side of the world will be able to see what is in front of you and direct you down the street.

This is a fabulous opportunity to see what is available.

The Webinar will take place on Tuesday 9th March, 2021 at 18:30

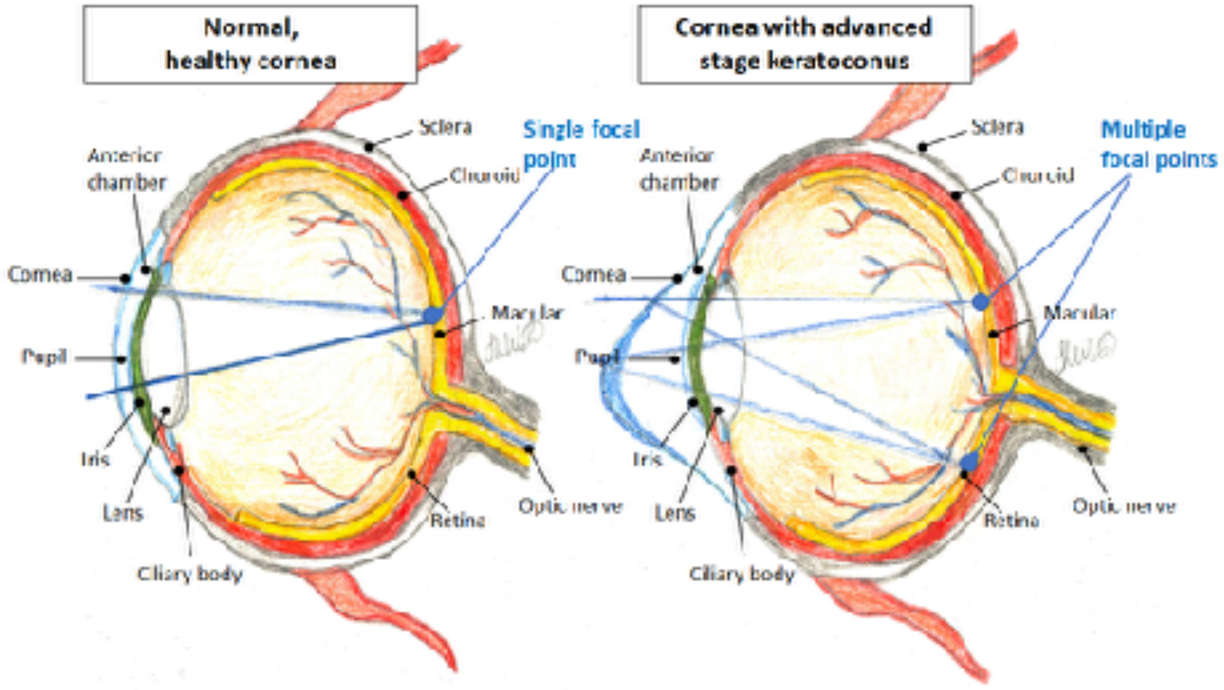
Register in advance for this webinar:
https://zoom.us/webinar/register/WN_L5pqj9INQ9uETw7_51nYgw
To save typing you can find the link by visiting the event post on our website.

After registering, you will receive a confirmation email containing information about joining the webinar.

Fight for Sight Small Grant Award

This is an excellent arrangement whereby Small Grants of up to £15,000 are awarded for research. Fight for Sight forms partnerships with charities like ours, each providing 50% of the funding. The advantage for Fight for Sight is that the charity’s involvement helps direct the investment into projects that are likely to be cost effective and beneficial. From our point of view it enables the KC Group to put the donations we collect to good use in the secure knowledge that Fight for sight will handle all the financial and compliance controls. Fight for Sight also ask an independent panel of experts to assess the applications for funding.

The object of our latest partnership is to develop a lab-based laser tool that is compact and portable, and therefore easier to use in both a lab and clinical setting. The tool will detect/monitor subtle biomechanical structural deficits that occur during early-stage corneal disease progression; specifically, localised thinning of the cornea.



Dr Samantha Wilson is leading the project at Loughborough University. She said: “The ability to understand, detect and diagnose corneal diseases, including keratoconus, at an earlier stage would mean that patients can receive treatment sooner. In the long-term, we expect that such devices will be routinely used by surgeons and ophthalmologists to detect, diagnose and treat corneal diseases before they have a significant effect on vision.” Visit our website for the full press release.

We are a Self-Help charity run entirely by volunteers

We depend on contributions from our members so, if you have any information to share or stories to tell we would love to hear from you

Well done Ashley Winter

Ashley continues his sterling work raising money and awareness.

He has published a book “Keratoconus and Me” and has now broken the Guinness World Record for the fastest male blind-folded mile at 10 minutes 11 seconds, in aid of Fight for Sight.

Keep up the good work Ashley - your efforts are greatly appreciated.

Mugs and T-shirts

We have a supply of mugs and T-shirts available in exchange for a small donation.

Simply email anne@keratoconus-group.org.uk for these or any other information.

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